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ABSTRACT

The paper examines the role of parents in the transition of developmentally disabled or otherwise handicapped persons into adult services. Because parents play an important role on the interdisciplinary team, parent training is important. This training can come in the form of university credit courses, workshops and mini-courses, self-help groups, and parent information networks. Such programs exist across the country. Obstacles to parent training include attitudes of professionals who assign all expertise and authority to the professional team, the lack of a coordinating agency to guide parents through the maze of available adult services, differing parental needs for adult disabled children, and lack of data concerning the needs of disabled adults. No mechanism currently exists to target state-of-the-art program information to parents of adults with disabilities; however, University Affiliated Facilities are well positioned to overcome obstacles to parent training in adult services through their programs of interdisciplinary training, exemplary service, and information dissemination. (DB)

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THE ROLE OF THE PARENTS IN TRANSITION PLANNING AND IN ADULT SERVICES

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THE ROLL OF PARENTS IN TRANSITION PLANNING AND IN ADULT SERVICE

Approximately one school generation after being guaranteed the right to a free, appropriate education for their handicapped child, a more sophisticated group of parents is becoming involved in adult service programs. Qualification for employment is an implied promise of American education, but between 50 and 80 percent of working age adults who report a disability are jobless (U. S. Bureau of Census, 1982; U. S. Commission of Civil Rights, 1983). Those adults with disabilities who are able to enter publicly-supported day and vocational services often experience low wages, slow movement toward employment, and segregation from their nondisabled peers (U. S. Department of Labor, 1979). Parents of children who negotiated "the special education maze" with difficulty, are disappointed to find their children do not have a secure future and now confront an even more complex maze of service systems without a central coordinating agency.

The Role of Parents on the Interdisciplinary Team

The interdisciplinary team process is especially important to adults who have developmental disabilities (Schalock, 1983). These adults are served by a wide variety of generic health, education, rehabilitation and social service agencies. No single agency is considered the coordinating point for service delivery to adults, as the schools are to younger disabled people. In order for adults to receive adequate provision for employment, living arrangements, and learning and adjustment,

"these systems must be infused with a certain number of participating professionals who have an interdisciplinary perspective and who have specific expertise in treating persons with developmental disabilities" (Ad Hoc Workshop, 1983). This interdisciplinary perspective is essential in helping parents understand the complexities of typical adult service programs.

Parents of developmentally disabled adults must be trained, and treated, as equal members of the interdisciplinary team. Public Law 95-602 (Developmental Disabilities Act) stipulates an interdisciplinary team will develop the Individualized Plan and requires the participation of the handicapped person and parents or other representative in the development of the Plan. Accrediting agencies, such as the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons (ACMR/DD), require an interdisciplinary approach to service delivery. ACMR/DD Standards 1.1.1-1.1.3 provide for and invite the active participation of the handicapped person's parent or advocate. The nature of services for developmentally disabled adults, together with public law and accrediting agencies, mandate an interdisciplinary planning process with parents considered as an integral part of the team. Schalock, Harper, and Genung (1981) report another important benefit from increased parental involvement. They found the two most significant predictors of successful community placement were the parents' acceptance of and involvement in community-based programs. All of these elements strongly support the involvement of parents

in the interdisciplinary team process which is especially important in the lives of adults with disabilities.

Parents as Professionals

In addition to serving as a professional parent (Patterson, 1983) on the interdisciplinary team, parents can be trained to be exemplary service providers. Parents have been highly successful advocates. Vincent et al. (1981) described parents as "best and lifelong advocates." Parents have also been successful behavior specialists and educational programmers. Parents can provide client-level and systems-level case management services (Schalock, 1983) and can be trained as employment coordinators. Parents bring special perspectives and sensitivity when they are trained as service providers and policy-makers for developmentally disabled adults. These important recipients and providers of training must be included in any plan for adult services.

CURRENT APPROACH TO PARENT TRAINING

Current approaches to parent training are varied. Intagliata and Doyle (1984) present an excellent review of supportive services and interventions for parents. One example is information and referral services that are designed to increase parents' knowledge about developmental disabilities and their awareness of available services. Another is self-help groups for parents which reduce the sense of isolation and uniqueness and provide much needed support by offering them the opportunity to share their feelings and experiences with other persons

facing similar stress. Training programs in behavior modification techniques have been helpful by increasing parents' knowledge of teaching skills and managing behavior problems. Respite care services exist to relieve parents from the physical exhaustion and continued psychological pressures of constant care. These varied approaches to training fall into categories such as university credit courses, workshops and mini-courses, self-help groups, and information networks.

University Credit Courses

University credit courses featuring a parent-oriented curriculum have much to offer parents of adults. The Georgetown UAF, through its linkages to George Washington University, administers a series of parent-oriented credit courses. Although the courses are not specific to parents of adults with developmental disabilities, course participants are expected to take a "life trajectory" approach to client services. Issues pertinent to handicapped adults and their parents are presented across topic areas which include: defining and describing the interdisciplinary team, its role function and composition; examining communication theory germane to team functioning; exploring the case management model; exploring the role of the case management in relationship to interdisciplinary teams; contemporary issues in public policy, legislation, and the judicial system; the evaluation of services, their current state and future directions; the various approaches utilized in interagency service delivery; and the nature and function of the role of an advocate. These excellent programs are directed by Maxine Fruend

and Eva Thorp. Also worth noting is an excellent parent training program coordinated by Luke Frank at the San Gabriel Valley Regional Center in California. This expansive program is offered in a community college setting and prepares parents to be certified as their son/daughter's case manager.

A unique element of the training plan is that participants are recruited through the existing network of community groups and agencies and return to that network as parent trainers. One result of this training is an action plan delineating the parent's responsibilities in the support of the sponsoring agency. These parents fully explore the nature of interdisciplinary teams, the special role of parents as case managers and the characteristics of effective team functioning and team management.

Finally, Intagliata and Willer (1981) provide a very comprehensive review of six training programs that have been developed for foster family care providers throughout the country. These training programs, some of which are offered for course credit in university settings (e.g., Dickerson, Eastern Michigan University) address a wide range of topics that would be quite relevant for parents of developmentally disabled children and adults. Broad topics include orientation to DD/MR; individual program planning; teaching self-care and community living skills; behavior management and effective utilization of support services.

Workshops and Mini-Courses

Workshops and mini-courses specific to parents of developmentally disabled adults are often convenient and helpful. The Georgia UAF and the Georgia Association for Retarded Citizens collaborated to provide workshops for parents of adults in day service centers across the state. Topics were generated through local needs assessment and issues such as adult vocational opportunities, adult day services, vocational services-education and rehabilitation, basic laws, quality standards for adult service programs, working with employers in private industry, parent communication skills, workshop organization methods and leadership skills were addressed.

In northern Virginia, Lee Bethel, the parent of a developmentally disabled adult, secured independent funding from a local bank to provide a mini-course for parents whose interests parallel hers. Topics center on legal and financial considerations and include: Why a will is needed; steps to securing SSI, Medicaid and Medicare; guardianship policies and issues; and establishing trust funds, insurance and estate planning for parents and families.

In Missouri, the Kansas City UAF conducts training workshops for parents with severely handicapped, developmentally disabled children and adults who are interested in participating in respite care networks that are being established. These workshops bring the parents together with individuals who are being trained to become certified respite care providers. The

workshops in which the parents, providers and clients participate deals with such topics as behavior management; meeting basic needs in such areas as feeding, bathing, toileting, lifting and carrying; orientation to developmental disabilities; living with a developmentally disabled person; communication; programming; medical safety and implementation of a respite care system.

Carl Calkins and Beth Gibson direct this respite training program. In addition the UAF is presently developing a respite care training package for use by the eleven regional centers which serve families and developmentally disabled clients throughout the state of Missouri. In this way, many more families and developmentally disabled persons will be able to use respite care services that have not been served previously in the state.

In Ohio, the Cincinnati UAF sponsors a training program for parents of adults with behavior disorders. This program has dealt with such topics as training in behavior modification, environmental analysis and prevention of behavioral outbursts. Yvonne Bullock Fryberger and Susanna Robbins direct this program.

Self-Help Groups

Groups providing emotional support for parents of handicapped children have received positive attention (e.g., National Parent to Parent Project). Many of these groups, notably the Pilot Parent Project in Kansas have expanded their scope to include parents of adults. The Competitive Employment Project which was directed by Tim Vogelsberg of the Vermont UAF, operated a support group for parents of employed developmentally disabled

adults. The group addresses such questions as "What are the vocational choices currently available to developmentally disabled adults?" "Do developmentally disabled adults move through a continuum of vocational placements?" "What are the benefits of competitive jobs versus activity centers of sheltered workshops?" "How will working competitively affect SSI and Medicaid benefits?"

Also relevant here is the program developed by Intagliata and Doyle (1984) for training parents in interpersonal problem solving skills. This program has as its objective to enhance parents' competence to build and maintain their natural support network (e.g., extended family, friends, neighbors) which are so essential to helping them deal more effectively with the challenges and stresses of raising a person with disability.

Parent Information Networks

Parent Information Networks located within each state are funded by the U. S. Office of Special Education and Rehabilitation Services. These networks provide information to parents of school age children on P. L. 94-142 and related special education laws and encourage parent participation in the educational process. No corollary exists for developmentally disabled adults.

A newsletter for parents is being published by the Virginia Commonwealth University Rehabilitation Research and Training Center. Members of the parent involvement team and contributors to the newsletter include Andy Beale, Mary Beth Bruder,

Patti Goodall, Sherril Moon, Fred Orlove, Buck Pentecost and Paul Wehman. The newsletter discusses issues such as why so many people with mental retardation, who are capable of working competitively, are still in special centers; the best way to determine if a person with mental retardation has good potential for competitive employment; how to deal effectively with professionals unwilling to consider employment services for one's son or daughter. The UAF satellite in Vermont operates a Parent Resource Project (directed by Richard Schutz) which publishes a parent newsletter. Although the newsletter is not directed solely to parents of adults, articles have included information on vocational services, secondary transitioning services, and adult employment. Other similar state newsletters are beginning to include topics oriented toward parents of adolescents and adults.

Summary

A variety of approaches to parent training/involvement and support exist nationally. They include information and referral systems, self-help groups, university courses, workshops and mini-courses. Few of these efforts are targeted solely for parents of handicapped adults. In instances where a "life trajectory" approach is taken, the needs of the handicapped adult and his parents are considered in program planning. Excellent parent-oriented programs deserving of replication exist across the country.

OBSTACLES TO PARENT TRAINING AND PROFESSIONAL ATTITUDES & ASSUMPTIONS

Donnellan and Mirenda (1984) document an important obstacle to parent training: the traditional parental view (often held by educators, psychologists, social workers, physicians and other professionals working with handicapped people) which assigns roles of authority and expertise solely to the professional team. These roles seem to reflect two elements: (1) preservice and professional training programs and (2) our society's attitudes and expectations about parent-professional training programs focused on the treatment, skill and methods acquisition needed to provide direct care to the client.

Often, little emphasis is given to developing the skills necessary to work effectively with professionals or other parents as a part of an interdisciplinary team (Darling, 1983). Medical schools and teacher training programs do not typically address (1) the parent's role in the educational or medical process, (2) family systems and how parents may react to crises, or (3) effective strategies for working with parents (Guralnick, Richardson, & Heiser, 1982; Wolraich, 1982). Donnellan and Mirenda (1984) imply that professionals feel unconcerned about being trained to work appropriately with parents. Parents have therefore been relegated to almost subservient roles as the grateful recipients of expert services (Lyons & Pries, 1983). Lartie (1975) describes the professionals' view of the "ideal" parent of a handicapped person as one who seeks out, understands, accepts, and rigorously follows professional

advice concerning treatment and programming. This "ideal" behavior will therefore result in progress and improvement for the developmentally disabled person. The antithesis of this behavior is exhibited by parents who question, modify or reject professional advice; who determinedly pursue difficult to deliver programming, or whose efforts are not producing positive outcomes for the client. These parents receive a label (equally as negative as any label given to a person with a disability) from the professional community and society (Darling & Darling, 1982; Rubin & Quinn-Curran, 1983). These professional and parental attitudes and assumptions are perhaps the most significant obstacles to effective parent training.

No Coordinating Agency

There is no way to sufficiently emphasize the problems presented to handicapped adults and their parents by the wide range of agencies providing services for them. Employment is rarely the immediate outcome of a public education for young handicapped adults, and their parents must be concerned with securing medical help, employment training or day service programs, alternate living arrangements, etc. Securing a coordinated program is a time-consuming and emotionally taxing ordeal. The lack of a coordinating agency or a point where "the buck stops" compounds the frustration.

NEEDS OF DEVELOPMENTALLY DISABLED ADULTS AND THEIR PARENTS

The parents of an adult with developmental disabilities have concerns which are very different from the concerns of

parents with a handicapped infant or child. Turnbell, Summers and Brotherson (1983) present stress points within family systems. Examples of stressors for parents in the launching (transition) stage include: adjusting emotionally to the adult implications of the handicap; deciding on an appropriate residence; initiating vocational involvement; dealing with issues of sexuality; recognizing needs for continuing family responsibility; dealing with continued financial implications of dependency; lack of socialization opportunities outside the family for handicapped member; planning the guardianship. Such issues are in sharp contrast to infant and school-age issues.

This stage in the family cycle is not often a consideration when planning parent support and training programs (Guralnick, Richardson & Heiser, 1982; Kroth, 1975), and constitutes another obstacle to effective parent programs in adult services.

In addition to consideration of parental needs, another barrier to preparing parents and others to work with developmentally disabled adults is an inadequate data base documenting vocational, residential, and learning and adjustment needs of those disabled adults (Will, 1983). These needs of developmentally disabled adults cannot be adequately addressed by parents or other service providers until an extensive needs assessment is completed. Lack of an adequate data base is another barrier to effective parent and adult programs.

Parent Characteristics

Parents of developmentally disabled adults are aging themselves. They may themselves be medically fragile or present

typical aging problems, e.g., reduction in income because of retirement. Parents of handicapped adults may be from minority groups who have difficulty accessing training and support systems. They may be financially unable to purchase training or services. They may live in rural areas and be unable to travel to urban areas to receive training. They may be unable to secure adequate child-care to allow them to participate in training or support programs (Boggs, 1979). These constraints often impede parent participation in training and service programs.

Summary

Several obstacles are significant in the successful integration of parent-oriented programs into adult services. Overwhelmingly documented in the literature are parental attitudes about "the doctor/social worker/teacher/psychologist is always right" being supported by professional concepts illustrating the "ideal" parent as being a compliant service recipient. These attitudes preclude effective parent participation in the interdisciplinary process and are both counterproductive and unnecessary.

In addition to the problem created by extant attitudes, insufficient data has been collected to document the needs of developmentally disabled adults or their parents. Little consideration has been given to documenting the needs of parents who have aging handicapped dependents. Specific information regarding developmentally disabled adults (e.g., where do they live; where do they work; with whom do they socialize) is scarce. Until an adequate data base is developed for these

adults, attempts to provide training and support programs for their parents will lack reliability and validity.

The quality of parent-oriented programs may be questioned as these programs are rarely offered as an integral part of university-based preservice personnel preparation courses. The nature of short term, non-credit courses do not lend themselves to close evaluative procedures, or to the interdisciplinary planning necessary to provide optimum training.

Characteristics such as parents' chronological age, socio-economic status, geographic location, and availability of child care have not been considered as an integral part of a comprehensive plan.

Until these considerable obstacles have been addressed in a comprehensive plan, adult service programs will fail to take advantage of the enormous resources parents have to bring to personnel development in adult services.

Conclusions and Recommendations

The interdisciplinary team is most important to developmentally disabled adults and their parents. Parents are mandated (by law and professional standards) as members of that team and should be trained -- and treated -- as equal partners. Parents of handicapped adults can also be trained as exemplary service providers (e.g., case managers, behavior specialists, respite care providers, educational programmers) and policy makers who bring special perspectives and sensitivity to direct services.

Current approaches to parent training and support are varied and rarely directed toward parents of developmentally

disabled adults. Across the nation, adult/parent-oriented exemplary programs, deserving of replication, exist as university credit courses, workshops, mini-courses, and self-help groups.

Significant obstacles prevent effective parent training in adult service programs. Professional/parent attitudes and assumptions about the roles of the interdisciplinary team are perhaps most important. Lack of a central coordinating point for handicapped adults is an overwhelming problem. An insufficient data base exists to document the actual needs of developmentally disabled adults and their parents. Characteristics of the parents of adults with handicaps are not usually considered in planning for services or training. A central information system is lacking and parent training programs seldom have a mechanism for quality control.

THE UAF ROLE

UAFs are well positioned to overcome the obstacles to parent training in adult services through their programs of interdisciplinary training, exemplary service, and information dissemination.

Interdisciplinary Training

UAFs which by definition provide interdisciplinary training to personnel serving developmentally disabled individuals, can facilitate the training of parents of disabled adults to participate as equal partners on the interdisciplinary team. In addition, UAFs can actively recruit parents to be trained to

provide direct services to adults. The thorough integration of parents in UAF interdisciplinary training programs can help correct the counterproductive attitudes which now exist.

Parents can be considered as both recipients and providers of UAF training. Parents can serve in both discipline-specific areas and as professional parent members of the team. Parents are able to contribute to the planning process by identifying training needs, service gaps, and issues pertinent to handicapped adults and their families.

UAFs can provide both quantitative and qualitative evaluation procedures (as specified by ADD, Ad Hoc Committee, and AAUAP Standards) for parent/adult oriented training programs. Interdisciplinary training oriented to parents of developmentally disabled adults can include university credit courses, workshops and mini-courses, support groups, and information networking.

Exemplary Services

UAFs can serve as an administrative coordinating unit for assessing the training and service needs of developmentally disabled adults and their parents. Many UAFs collect state needs assessment data pertinent to the needs of school age children. UAFs can now begin to collect needs assessment data specific to vocational, residential, and learning and adjustment programs for adults with disabilities and their parents.

Existing UAF state training networks (such as those in Kentucky, Georgia, Iowa, and Maryland) can begin to consider issues pertinent to developmentally disabled adults and their

parents. These training networks can begin to generate comprehensive parent-oriented training plans specific to adult services, which emphasize employment incentives, interagency cooperation, and resource sharing.

Excellent service programs for adults with disabilities and their parents are in place across the country. Regional UAF networks provide an ideal setting for coordinated replication efforts. Regional networking affords each UAF the opportunity to replicate service programs for disabled adults and their parents based on documented state needs and suited to each UAF's area of specialization. Parent-oriented service programs should be based on state needs assessment and be considerate of the characteristics and needs of handicapped adults and their parents.

Information Dissemination

No mechanism currently exists to target state-of-the-art program information to parents of adults with disabilities. Excellent Parent Information Networks, which train parents of school age children in their rights and responsibilities under P.L. 94-142, provide these parents with current information in each state. UAFs typically work closely with their State's Parent Information Network and research and training centers. A UAF coordinated effort could develop methodology and funding sources to extend this type of information sharing to parents of handicapped adults. Information dissemination which UAFs provide by definition can provide significant assistance to

parents confronting the complexities of adult service programs. Increased parent involvement will result in better coordinated and more fiscally appropriate programming.

In sum, parents have an important role to play in personnel development in adult services. UAFs have certain characteristics (e.g., interdisciplinary training, exemplary services, information dissemination) which make them ideal coordinating units for parents of adults with developmental disabilities. UAF networks can develop comprehensive plans for training personnel to serve disabled adults. The resources and needs of their parents should be an integral part of this interdisciplinary effort.

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